

Briefing on the Data (Use and Access) Bill

1. About the National Data Guardian (NDG)

The National Data Guardian (NDG) role was [created in November 2014](#) to be an independent champion for patients and the public when it comes to matters of their confidential health and care information. The [Health and Social Care \(National Data Guardian\) Act 2018](#) places the NDG role on a statutory footing and grants it the power to issue official guidance about the processing of health and adult social care data in England.

The NDG's vision is to improve the quality and sustainability of health and care through the safe, appropriate, and ethical use of people's health and social care information. This is achieved by providing leadership, expertise and insight on the use of health and social care data, advocating for policies, practices and principles that build and maintain trust in data use and the confidentiality of our health and social care services.

2. Summary

The Data (Use and Access) Bill is an important regulatory step in creating a legislative landscape that supports the rights and freedoms of data subjects, whilst enabling the safe, secure and appropriate use of data in ways which benefit the public.

I welcome the provisions in the Bill which will provide a legislative foundation to support standardisation of information technology across the health and social care system. Standardised and interoperable information technology will drive efficiency which will have significant impacts on patients and the staff who care for them.

However, I am concerned with the weakening of transparency obligations in Clause 77 of the Bill. Transparency is a fundamental aspect of earning and maintaining public trust in health and social care data use. As such, any weakening of transparency obligations has the potential to negatively affect people's trust in how health and social care data is used for research. Any erosion of public trust would negatively affect public perceptions of, and sentiment towards, important ongoing and forthcoming health data initiatives.

3. Support for Schedule 15: Information standards for health and adult social care in England

The complexity of IT systems within the NHS poses a significant barrier to the efficient use of health and care data for both patient care and broader public benefit.

The [Sudlow Review](#) states that many different computer systems are used by many different NHS organisations. While some software systems are developed in-house by the NHS, most are provided through contracts with multiple commercial suppliers. This fragmentation results in a lack of interoperability, which hinders the sharing of vital patient information between different parts of the NHS and social care system.

[Previous governments have acknowledged](#) the challenges posed by the lack of digital interoperability within the NHS. The provisions in the Bill empower the Secretary of State to request that commercial IT providers comply with interoperability standards set by the NHS. Consistent with [my longstanding support](#) for aligning data standards across the NHS and social care, I strongly support this legislative drive to enhance digital system interoperability. Enabling seamless information flows will have an enormous impact on NHS employees' time, ultimately delivering substantial benefits to patients.

4. Clause 77 Information to be provided to data subjects: risks eroding transparency and damaging public trust in how health and care organisations use and process people's data.

The principle of transparency is a cornerstone of the UK GDPR, UK data protection legislation and [ICO guidance](#). Current transparency obligations may be satisfied using a range of techniques to reach large numbers of data subjects without necessarily requiring direct contact with each individual.

There is an exemption from transparency requirements for research purposes where provision might involve disproportionate effort, but this applies only when data has not been obtained directly from the data subject. Currently, this exemption does not extend to cases where personal data is collected directly from the data subject.

However, Clause 77 of the Bill seeks to remove the existing requirement to provide transparency information when personal data are collected directly from the data subject and subsequently processed for Research, Archiving and Statistical purposes, if meeting this obligation would require 'disproportionate effort'.

When personal data is collected directly from the data subject, there may be opportunities and mechanisms which can be used to provide transparency information to them. This does not necessarily require individual contact with each data subject; it can be done through appropriate communications channels, such as privacy notices, websites, newsletters, communications which are directed at interested groups or by placing transparency materials in settings where data is collected or where research is undertaken.

The exemption from the requirement to be transparent where this would 'involve a disproportionate effort' would erode the health and social care system's long-standing commitment to the principle of transparency, and stands in stark contradiction to recent [ICO](#)

[guidance](#), which sets out the ICO's expectations for transparency in organisations processing health and social care data.

Both I and my predecessor have consistently stressed that a fundamental aspect of earning and maintaining public trust in health and social care data use is ensuring there are '[no surprises](#)' in how data is used. I have significant concern that any legislation that seeks to diminish transparency could undermine public trust in health and care research.